

CenterPieces

Sharing our Activities in Research, Education & Clinical Innovation to Advance Healthy Aging

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Volume 2: Dementia Caregiving Research at CARAH

Helping Caregivers to COPE

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Margaret Kimato, after he passed, she wasn't prepared for the challenges to come. Shortly after he passed, Margaret became increasingly forgetful and delusional. Deb attributed her mother's memory loss to the stress of losing her husband. With time, however, Margaret's condition worsened and she was diagnosed with Alzheimer's disease.

As the primary caregiver of a parent with Alzheimer's, Deb dealt with various complications beyond the memory loss. Her mother continually roamed the house in the middle of the night, for no apparent reason. It turned out that her irregular sleep patterns were due to arthritis in her arm as well as painful kidney infections. Deb had a hard time gauging her mother's pain because her mother couldn't articulate it.

"I carried a lot of guilt since I didn't know about Mom's pain," admits Deb. "She can't describe her current pain, so I've learned to look for non-verbal clues."

Awareness of non-verbal clues of pain was just one of the techniques Deb learned through her participation in Project COPE. Project COPE is a study designed to help caregivers learn new ways to manage the challenges of caregiving and is conducted by the Center for Applied Research on Aging and Health (CARAH) at Thomas Jefferson University.



Deb Lackman with her mother Margaret.

Project COPE is funded by the Pennsylvania State Department of Health Tobacco grant funds as part of the Pennsylvania Center of Excellence in Alzheimer's disease awarded to the Farber Institute for Neurosciences at Jefferson.

Deb was drawn to Project COPE because it focused on both the needs of caregivers and the quality of life of patients. Dr. Laura N. Gitlin, the principal investigator of the study, explains, "Project COPE builds on over 15 years of research conducted by CARAH on family caregiving and dementia care. Taken as a whole, these studies show that there are various non-pharmacological approaches that families can use to effectively manage this devastating disease and enhance the well-being of their family member with dementia and themselves."

Tracey Vause-Earland, clinical coordinator and one of the occupational therapy interventionists at CARAH, worked directly with Deb in her

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Newsletter of the Center
for Applied Research on
Aging and Health (CARAH)

Jefferson College
of Health Professions

Thomas Jefferson
University

Message from the Director

Welcome to the second issue of CenterPieces, the newsletter of the Center for Applied Research on Aging and Health. We dedicate



caregiving, a critical public health issue. There are 26 million individuals with dementia worldwide, and approximately 5 million individuals with the diagnosis in the US. This number may exceed 16 million in 2050.

For the past 15 years, CARAH has been in the forefront of developing and testing innovative approaches to supporting families in their heroic care efforts and enhancing the quality of life of affected individuals. CARAH's current research focus is on testing non-pharmacological approaches to managing one of the most complex aspects of the disease, disruptive behaviors.

We remain deeply indebted to the many families who have shared their stories and knowledge with us so that we may learn from their experiences as we work together to identify the best approaches to manage the disease. In this issue, you will learn about research studies conducted at Jefferson and the important role of clinical trials in helping to identify effective dementia treatments.

If you are a caregiver, know someone who is caregiving, or a health provider working with families dealing with dementia, we invite you to contact us to learn more about participating in our studies. Call us at **215-503-2897** or visit our web site at www.jefferson.edu/jchp/carah.

Speaking With Barry Rovner, MD

Q: What Alzheimer's related studies are you involved in currently at the Farber Institute for Neurosciences?

Dr. Rovner: We are evaluating three exciting new disease-modifying drug treatments that may slow down the course of Alzheimer's disease. I am also a Principal Investigator of Jefferson's Center for Excellence in Neurodegenerative Diseases funded by

the Pennsylvania Department of Health Tobacco Settlement grant. We are testing innovative screening methods to identify dementia in community-based agencies serving older adults, as well as

testing in-home skills training services to delay nursing home placement and reduce stress for a racially diverse group of family caregivers. This latter study is being conducted at the Center for Applied Research on Aging and Health, by Principal Investigator Laura N. Gitlin, PhD.

"Participating in research allows families ...to get potentially beneficial treatments for their relatives before they are available to the general public."

Q: What do study participants gain from being part of these research studies?

Dr. Rovner: We have learned that families derive a lot of hope and support from participating in these trials. In general, participating in research allows families to have the opportunity to get the best possible care for their relatives, including potentially beneficial treatments before they are available to the general public. Being a participant may lead to a decrease in the stress of

Did You Know?

As many as 80 percent of persons with dementia are cared for in their homes by family members.

caregiving, as well as provide the chance to make a contribution to new scientific knowledge. It is an opportunity to share personal experiences so that others may benefit.

Q: Are there any risks of participating in drug trials?


Dr. Rovner: With trials of medications, there are always some risks of side effects, however we closely monitor any possible adverse reactions. Drugs being studied have already been tested before so that we can assure that they are reasonably safe. ■

Contact information for Dr. Rovner

phone: 215-503-1254

fax: 215-503-1992

email: barry.rovner@jefferson.edu



Dr. Barry Rovner is Professor of Psychiatry and Neurology and Director of Clinical Alzheimer's Disease Research of the Farber Institute for Neurosciences. The focus of his research is to test novel interventions to improve cognition, prevent depression and enhance quality of life for older adults.

Helping Caregivers to COPE *Continued from page 1*

home to instruct her on practical methods she could use to cope with her mother's progressive illness. She began by assessing Margaret's cognitive level as well as Deb's caregiving goals, understanding of the disease and willingness to learn new strategies. She found that Margaret had a high cognitive level and was receiving unnecessary help from her caring daughter. "Out of concern and an unclear understanding of her mom's abilities, Deb was actually helping her mother too much. Deb needed to learn more about the disease and she was open to new knowledge and adapting strategies to manage better day-to-day," says Vause-Earland.

Based on the assessments, Ms. Vause-Earland designed an "action plan" for Deb to follow. The plan included specific behavioral goals, a summary of Margaret's abilities or what she could still do, and specific strategies for Deb to implement to enhance her mother's participation in daily activities and decrease her boredom and anxiety. Since Margaret was once a housewife, Ms. Vause-Earland

suggested activities such as washing dishes or folding laundry — pain-free activities that brought her satisfaction, a sense of accomplishment, and reflected her previous roles and interests. Ms. Vause-Earland also helped to establish a nighttime routine for Margaret: no coffee, taking a bath, playing soothing music and using a nightlight. The nightly routine prepared her for bed in a relaxed manner and reduced her erratic nighttime behavior.

Beyond these strategies, Ms. Vause-Earland taught Deb how to build her own sense of efficacy as a caregiver. Through stress-relieving techniques and positive reinforcement, Ms. Vause-Earland gave Deb confidence and built her self-esteem. "Tracey taught me that I didn't need to do everything for Mom; that it was okay to let go. She was the first person to tell me that I was doing a good job," says Deb.

Ms. Vause-Earland saw Deb transform as a result of her participation in Project COPE.

"Deb's energy and enthusiasm and readiness to integrate new strategies into her daily caregiving transformed her situation," asserts Vause-Earland. "By the end of her participation in the study, she had much more confidence in her abilities and a sense of mastery. Deb now feels empowered, more in control of her situation."

Today, Deb is successfully coping with her mother's disease and both are much happier as a result. "My mother now feels like she's part of the family, rather than looking in from the outside. She's happier now that I'm letting her be her. She is what she is today. You enjoy it and celebrate it. A tremendous burden has been lifted off of my shoulders."

CARAH is still enrolling participants for Project COPE. For more information or to enroll in the study, please call **215-503-2897**. ■

This article appeared in the July 18-31, 2007 edition of the *City Suburban News*.

We Are Seeking Participants for the Following Studies

Title: Medical Treatment Preferences

Funding Source: National Institutes of Health

Principal Investigator: Susan M. Parks, MD

Target population: Family members 70 or older who serve as proxy decision makers

The purpose of the study is to find ways to improve advance directives, medical counseling for family members, and training of clinicians who care for patients with life-limiting illnesses.

Telephone interviews will be conducted separately with people 70 or older and their relatives who they designate as likely proxies (whether or not they have power of attorney or other legal arrangements). Participants are asked their opinions about several types of treatment, both life-prolonging treatments, as well as questions about health, mood, and physical functioning. ■

Title: The Morality of Giving Care to a Demented Mother

Funding Source: National Institute on Aging

Principal Investigator: Helen K. Black, PhD

The purpose of this study is to examine the experience and meaning of caregiving to daughters who have been the primary

caregiver to their demented mother for at least 6 months. The research interview is conversational and includes questions about how the daughter came to be the primary caregiver for her mother, and the accomplishments, difficulties, joys and stresses that occur with caregiving. ■

Title: Project COPE

Funding Source: PA Department of Health

Principal Investigator: Laura N. Gitlin, PhD

The purpose of this study is to evaluate a program of in-home services to address family caregiver upset and boredom, depression, and troublesome behaviors in persons with dementia. Participants are assigned by chance to one of two groups. One group receives services from an occupational therapist (OT) and a visiting nurse. The nurse examines the client to identify possible medical problems. The OT works with family caregivers to identify the potential behavioral triggers of their

relative's problem behaviors and designs a tailored program of activities to address these behaviors. ■

Title: Health-related Quality of Life in Persons with Dementia Living at Home

Funding Source: Alzheimer's Association

Principal Investigator: Laura N. Gitlin, PhD

This 3 year study will examine the quality of life of individuals with dementia who are living at home. Family caregivers will be interviewed about their perceptions of their quality of life and that of their family member. Individuals with dementia will be asked to participate in brief assessments of their functional and cognitive abilities, activity interests and other health-related factors. The study seeks to identify the factors that support or serve as a barrier to quality of life that can be modified. Families that participate will receive a written report of health and functioning of the person with dementia. ■

All participants in our research projects receive compensation for participating in study interviews.

For further information about these and other studies, please visit our website at www.jefferson.edu/jchp/carah or call **215-503-2897** to speak to a member of our staff.

If I Decide to Participate, What Will I Be Asked to Do?

You will first be asked some questions over the phone to make sure that the study you are interested in is right for your situation. For some studies a trained interviewer will then come to your home at a time that is convenient for you. The interviewer will first explain the study, review the benefits and any minimal risks of participation, and ask you to sign an Informed Consent form that describes the study procedures and acknowledges your willingness to participate. You also will have an opportunity to ask any questions and decide whether you want to participate. If so, the interviewer will conduct the first interview, and will then review with you the next steps of your

participation, depending on what study you are participating in.

Am I protected as a study participant?

All research studies must be approved and continuously monitored by an Institutional Review Board (IRB), a legal entity of a sponsoring institution. The IRB ensures that you are protected from risks that may be too great, that your privacy is protected and that you are completely informed about the study and have chosen freely to participate.

In addition, if you participate in research projects at CARAH, your confidentiality will be protected. All information we

receive is stored in locked cabinets that is only accessible by members of the project team. Your name will never be identifiable on any of the information you provide. ■

Did You Know?

Caring for someone with dementia is associated with a higher level of stress than caring for someone with functional impairment from another type of chronic illness.

Center for Applied Research on Aging and Health

Coping TIPS for Caregivers

- Educate yourself about the disease your family member is facing and how it may affect his or her behavior, pain level or quality of life.
- Find sources of help for caregiver tasks. Contact family, friends, neighbors, church/synagogue, workplace, Area Agency on Aging or other organizations.
- Protect your personal time for something you enjoy or something you need to get done.
- Find time for exercise, eating well and sleeping enough. This will help you to be better able to provide care.
- Use your personal network of friends and family for support or find a support group for caregivers of dementia patients in your area.
- Be in touch with your own feelings of sadness (crying more or sleeping more or less than usual, increased or decreased appetite or lack of interest in usual activities). These may be symptoms of depression. Talk to your doctor if you experience these symptoms.
- Consider how you feel and what you will do after caregiving ends.

Key Resources

Alzheimer's Disease Education and Referral (ADEAR)

1-800-438-4380

www.niapublications.org/adear/

Alzheimer's Association

1-800-272-3900 (helpline)

www.alz-delawarevalley.org/

The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss in Later Life

Authors: Nancy L. Mace, MA and Peter V. Rabins, MD, MPH

Contact Us

130 S. 9th Street, Suite 500 Philadelphia, PA 19107

Telephone: 215-503-4716

Fax: 215-923-2475

Website: www.jefferson.edu/jchp/carah

For inquiries regarding articles in *CenterPieces*, or to receive electronic copies of this newsletter, please contact the editor, **Sandy Schinfeld, MPH** at sandy.schinfeld@jefferson.edu.

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130 South 9th Street, 5th Floor
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